

Oxfordshire MNDA

Branch Newsletter

Autumn 2023



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The Annual Summer Event marking another year of progress for the Oxfordshire Branch



On Saturday 20th May we enjoyed another rewarding and well attended summer event at Christchurch Hall, Abingdon. We were joined by many people with MND and their families as well as fundraisers, volunteers and supporters. Amanda Devlin, Regional Fundraising Lead gave an informative report on the 5 Promises that have been adopted by the MNDA as their guiding principles. They are:

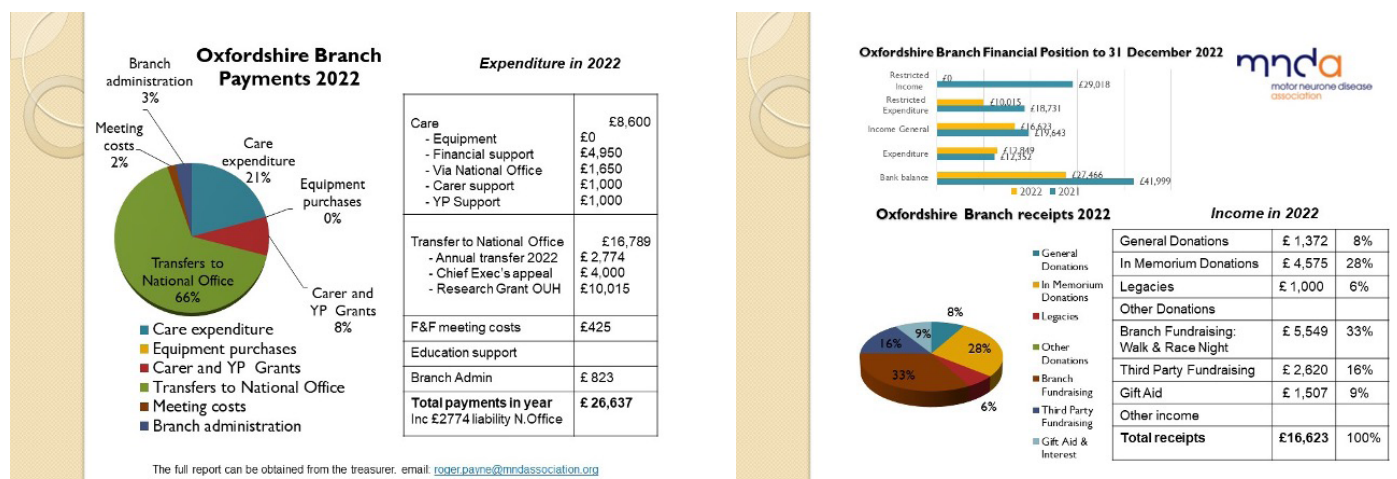
1. MND is treatable and ultimately curable.
2. PWMND get the care they need when they need it.
3. Every day counts
4. PWMND are heard
5. No one face MND alone

As a branch we are also committed to those promises and by working together in partnership with all those affected, with our volunteers, with our fundraisers and with our MNDA officers we will continue to make our vision a reality, that is a world free from MND.

At the summer event we were delighted to welcome some of our important fundraisers including four from the North Oxfordshire Caravan Club and the Chair and colleague from the North Oxfordshire Rotary Club. It was an even bigger surprise when the Rotary Club surprised us with another generous donation. We are continually amazed at the generosity of our supporters.

Martin McLeman

Branch treasurer, Roger Payne produced his annual report at this event about branch finances in 2022.



MND Connect is available 9am to 5pm and 7pm to 10.30pm Mondays to Fridays.

0800 802 6262

Lesley Ogden reported that the branch has been pleased to see attendance at Family and Friends support meetings increase through the year to pre pandemic levels which means that they are found to be valuable in both in the north and south of the county. Applications for grants to the branch have also increased over the last year too and are much appreciated by those who receive them. We are extremely grateful to fundraisers and donors to branch funds to be able to respond in this way.

Meetings are not the only way we provide support for our members living with MND and their families. There is a lot going on between with individual support particularly by our five dedicated Association Visitors who keep in touch by email, phone calls, texts and visits to those who want individual support.

The post for a psychologist one day a week at the Oxford Care Centre funded for two years by a branch legacy has proved itself to be much needed by many who have accessed appointments with Rachel Woolrich and found them so helpful. In addition she has worked hard to produce all the evidence needed to prove and expand this service after the end of the project. The branch appreciates its close connection to the Oxford MND team.

The Family and Friends Support Group....

The weather was perfect for our summer visit to **Millets Farm** Centre this year while strolling round the site and especially in Webbs Garden Centre where some plant and ornamental purchases were made.

After this we all met together in the Flower Market café to indulge in cakes, ice creams and various drinks. The pink smoothie looked really tempting and exotic! Having re-organised the table and chairs quite a bit to accommodate the large group of 20 to be able to sit together, everyone was seated and then a very helpful senior waitress called Sylvia patiently took the orders from everyone - a daunting task. It was not long before the orders arrived served by other waiting staff with good humour and efficiency.

Everyone seemed keen to chat and communicate which made for an enjoyable afternoon in a friendly atmosphere and new contacts were made while regulars were pleased to see each other once again. Appreciative comments were made as people left so the afternoon visit was considered a success.

Lesley Ogden

Matthew Hollis our MNDA Area Support Co-ordinator stepped in to run the **Banbury** meetings in June and August as Dave Vale who has organised them in the past is unable to do so – we send Dave our best wishes and thanks.

Matthew reports...

We held another **Banbury support group** on 27th June at Banbury Cricket Club, which was attended by 4 people. Although it was a small gathering, it is a very friendly group in nice surroundings and we had lots of different and interesting conversations, including sport and, dare I say it, Christmas! Another meeting is due on 15th August.

Next dates for Family and Friends Support groups

Wednesday 27th September 2-4pm at Wytham House, Farmoor, Oxford

Tuesday 10th October 2-4pm Banbury Cricket Club

Wednesday 22nd November 2-4pm Lounge room at Christ Church, Abingdon



No One Knows What To Say

**My brother came yesterday
He hugged me so tight
I couldn't breathe.**

**It's distressing that my illness
makes my family distraught no line spaces until
my friends shocked.
No one knows what to say**

Marion Dorrington has published a book of her poems recently. The cover is illustrated by one of her paintings. She is offering copies for a donation to the Oxfordshire branch at

<https://www.justgiving.com/fundraising/oxfordshirebranchmnda>

She says that her writing was inspired by her poetry - loving mother and her daughter who started her writing her own poems after visiting a poetry class.

“It was scary because we had to write a poem in the class. But I was reasonably successful and it took off from there. The poems reflect on my childhood in Rugby and my life in Oxford, including 35 years as a GP.” The more recent ones about her diagnosis with MND has helped her come to terms with her illness she says.

Copies will be available at our meetings or through the branch contact email: lao.ogden@googlemail.com.

Three cheers for our fantastic Fire and Rescue service!

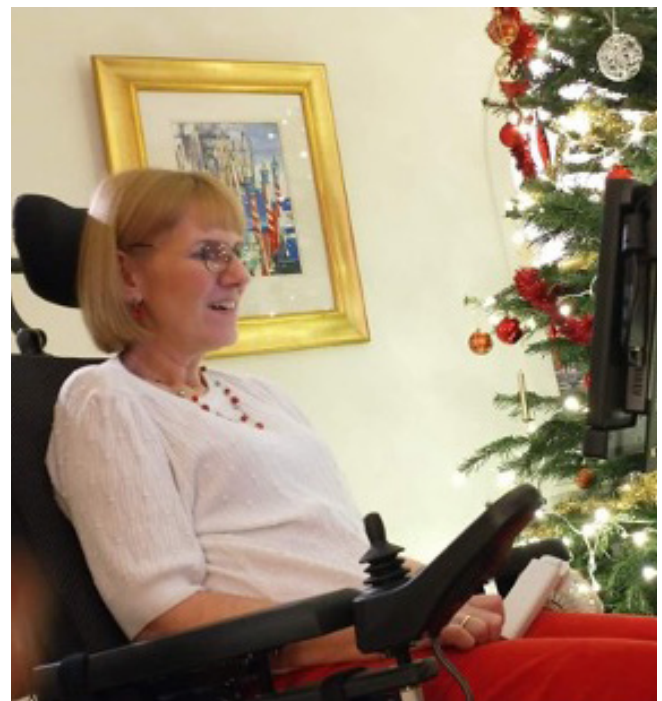
Susan Fletcher Watts had quite an adventure after she visited friends for a Ruby Anniversary lunch back in March. This is her story

We arrived home and started the lengthy process of unloading me in my Quickie electric wheelchair.

Problem: the rear door of the wheelchair accessible vehicle wouldn't open. Try again Brian. He did. Bigger problem; it still wouldn't open. I was completely trapped, sitting in the back between two immovable seats. The only option was to call 999.

The fire brigade were totally brilliant. Within 15 minutes we heard the comforting sound of the siren. Four burly chaps jumped out from the blue flashing fire engine (which completely blocked our lane) and came to my rescue. Meanwhile friend Neville kept me wrapped in blankets whilst Brian answered questions about ramps and locking mechanisms. It took 40 minutes and involved noisy sawing of the catch and crowbarring the door open, but eventually I was freed.

Phew!



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This year's Southmoor Village Fete raised £538

Jill Garner and I had collected many, many unwanted gifts and recyclable goods for our stall at the Village fete. It is held in the lovely grounds of Kingston house and there was a great variety of stalls.

The day dawned and it was really beautiful we had two tables of goods and a raffle. The fete was well attended and we raised £538 - an amazing amount.

We were extremely grateful to those who donated or bought items and took part in the raffle - a very memorable day. This will be matched by funding from Lloyds bank thanks to Linda Proto who was a former employee.

Sue Butler



Fundraising and awareness

Please let us know about any fundraising or awareness campaign and we will include your story or event in the next newsletter. Information and photographs supplied to the branch secretary Lesley Ogden at: lao.ogden@googlemail.com

Campaign to help raise awareness of carers' rights

MNDA research has shown that 75% of carers have not had a Carer's Assessment to which they are entitled to help with the challenges of caring.

Support MND Carers where you live

If you've got a little more time, why not ask your local council about what they are doing to promote access to carer's assessments?

The MND Association has a handy [template letter](#) to help you write to your local councillors highlighting the need to improve access to carer's assessments.

Let them know what you hear back!

Please share this [carer's assessment infographic](#) on social media and among your social networks.

More information about support for carers of people with MND www.mndassociation.org/CaringSupport

Your right to a carer's assessment 

For more information visit MNDAssociation.org/CaringSupport

What is a carer's assessment?
A carer's assessment enables you to tell adult social care services how your caring role could be made easier.

You should be offered an assessment once you have been identified as a carer, or you can ask for one. Contact your local authority or, in Northern Ireland, your local health and social care trust.

You have a right to a carer's assessment whether or not you live with the person you support. You may provide care full-time or part-time, or combine care with paid work.

The assessment does not judge your capability as a carer, but allows you to review your caring role:

- Do you need help and are there services that could support?
- Are you willing and able to carry on caring?
- Can you continue to give increasing levels of care?

The person you support doesn't need to have had a social care assessment.

An assessment will help you find out about:

- care services, benefits advice and local voluntary organisations
- planning for respite, urgent or emergency care
- assistance with travel
- how to maintain your own interests, studies or activities while caring
- suggestions for counselling or support groups.

Motor Neurone Disease Association
Francis Crick House,
6 Sumnerhouse Road,
Moulton Park, Northampton NN3 6BU, UK
www.mndassociation.org
MNDAssociation.org/SupportMNDCarers

SUPPORT MND CARERS

We never lose hope. We strive to find a cure for MND, and to support everyone affected by this devastating disease

facebook.com/OxfordshireBranchMNDAssociation

MNDA Care Showcase Boughton House



Lesley Ogden, Secretary and Martin McLeman, Chair were very privileged to have been invited to the MNDA Care Showcase on 6th June hosted by His Grace the Duke of Buccleuch and attended by over 100 volunteers and fundraisers and also attended by our Royal Patron HRH The Princess Royal.

The work of the National Care team and the crucial financial support offered was highlighted by a number of speakers who were living with MND and illustrated just how challenging the financial situation is.

Access to financial support is critical for all living with MND and if you are reading this article wondering how to make ends meet then please don't hesitate to contact anyone at the Oxfordshire Branch. We won't rest until every day counts.

Martin McLeman

It was great to represent the branch at this event and to meet Richard Brailsford our local Oxfordshire fundraiser and others who raise all important funds and awareness for the MND Association as well as some volunteers from other branches in the country who attended. It was very interesting to share experiences and ideas and to hear about the progress made in support and care. It was a day that inspired us to re double our efforts.

Read more about Richard in his article.

Lesley Ogden

Articles for this newsletter are always welcome, particularly from our members. If you no longer wish to receive the newsletter contact Matthew Jones msg4matt@gmail.com or Lesley Ogden lao.ogden@googlemail.com and if you prefer to have your copy by post.

Does this interest you?

The branch are looking for someone to take on collating articles for the newsletter for a fresh look and new ideas as Lesley has been doing so for a number of years. Guidance will be given and Matthew Jones will still produce it in it's attractive format.



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£43,000 raised for research into MND by inspiring Oxfordshire fundraiser Richard Brailsford and the MND Army



Richard is second on the left in this photo with his supportive family

My friends, family and I have been raising money since 2013. The year our Dad died after a 9-month battle with MND.

Although dad's rapid illness meant I didn't have time to think of fundraising, afterwards we wanted to do something in memory of Dad. We completed a tough 26 mile walk in Derbyshire that Dad and I had previously done. Called the White Peak Walk. North Oxford Lawn Tennis Club also chose MND Association the same year for their charity tournament.

Fundraising then involved many challenges. We completed the 16 mile Baslow Boot Bash, London to Brighton, off road mtb challenge, 100 miles off road on The Ridgeway and others.

After watching My Year with MND, about Rob Burrow I asked several others to get involved. During lockdown, as rules were relaxing. Then friends and family in Oxfordshire, Sussex, Derbyshire, Norfolk, North Wales and even France got involved. Challenges included 7 peaks in 7 days in North Wales (including Snowdon), multiple 7 days of running (including a half-marathon) and big walks. Our youngest son, Jack wanted to do a challenge for Grandad. Jack came up with doing 7,777 kicky ups in 7 days. My sister's family did 7 long walks up in Derbyshire. With the support of The Hair and Beauty Forum in Witney we have run several raffles and more ideas are planned for our fifth year of fundraising.

I feel blessed to have friends who care so much about those with MND.

The icing on the cake was when our friends, Chris and Mish who own Woodstock's The Duke and The Back Lane offered to support us. Customers have an optional 50p added to their bill. This idea has already raised around £10,000 (a lot of 50ps!!) and as a group we have raised nearly £43,000.

Fundraising has allowed us to turn a devastating, desperate situation into a hopeful, positive one. The MND Army has created a hugely positive environment, raising awareness and allowing a much wider network of fundraising across the UK. The team has generated way more money than I would have raised on my own. Everyone who has taken part has told me how good it has been for their wellbeing, and sense of purpose. What they have done has taken us to a new level.

We want a cure. It's as simple as that. 100% of the money goes into ethical research. If we all keep all working together we will beat Motor Neurone Disease. We just want to remove one word from a sentence; there is NOT a cure for MND.

Please support our fight to find a cure for Motor Neurone Disease: <https://www.justgiving.com/fundraising/the-mnd-army-at-10>

Please listen to our podcast, with MND Association <https://podcasts.apple.com/gb/podcast/mnd-matters-episode-23-3-richards-fundraising-story/id1560505646?i=1000595518577>

We never lose hope. We strive to find a cure for MND, and to support everyone affected by this devastating disease

facebook.com/OxfordshireBranchMNDAssociation

Join us for the 12th Annual Branch Walk in Blenheim Palace Park with your family and friends



Jill Garner, the Walk organiser says

I hope you all had a wonderful summer and are looking forward to the Oxfordshire Branch Walk 2D'Feet for MND. It will take place on:

**Saturday 7th October 2023 at Blenheim Palace Park
for a prompt start at 1pm**

It is always a popular gathering of committed people with the aim of supporting and remembering those with MND. It will involve a 2 mile or 5 mile loop of the beautiful grounds and will raise funds and awareness for the MNDA Oxfordshire Branch to support local people affected by MND as well as contributing towards the care, support and research provided by the MND Association.

The cost per adult is £12 (free for children) and you will receive a T-Shirt and access to the grounds for the day. Please come along from 11.30am with well-behaved dogs and children and enjoy a wonderful day. Volunteers will be there on the day to help direct, support and push if needed.

For more information contact me on Jill.Garner@outlook.com.

Please fill in a registration form by 30th September so we can manage numbers and order enough T shirts. Sponsorship is very welcome but not essential. Forms are available from Jill or on a link to the branch website at:

www.mndassociation.org/support-and-information/localsupport/branches/oxfordshire-branch/

Payments/ Donations can be made on
www.justgiving.com/page/oxfordshire-branch-walk-2dfeet-2023



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